

FRAGILE X ASSOCIATION OF AUSTRALIA
ANNUAL GENERAL MEETING
Sunday 20 November 2022, 3:00 pm AEDT
By Zoom
DRAFT MINUTES



The meeting opened at 3:00pm. In attendance by Zoom:

1. Ted Brown (Chair),
2. Wendy Bruce (Executive Director), Liz Jewell (Counsellor)
3. Members: Cynthia Roberts, Adam Lawrence-Slater, Karen Lipworth, Phil Eastbury, Jennifer Busch, Graham Hook, Rosie Donald, Bruce Donald, Godwin Galea, Janine Peate, Mandy Barker, Penelope Figgis, Damon Hoole, Elaine Hoole, Melinda Good (and Jeremiah Good), Nyleta McRae and Andrew, Doug Rodgers, Nada Jaafar, Robyn Iredale, Tim Turpin, Pat Van Der Mey, Belinda D'Amico, Kate McKeand, Amy Miceli, Alison Evans, Mandy Barker, Mary Barker, Rebecca Wellbrock, Jacqui Smith-Horak, Natasha Smith-Horak, Alison Evans, Rebecca Wellbrock, Joan Parkes.

The quorum for the meeting (30 persons) was reached.

1.	Welcome – Ted Brown
2.	Apologies: Mr John Cunningham AM; Mrs Margaret Cunningham; Kim Preece; Martin Davey; Mike Tozer; Helen Tozer; Joanne Ryan; Sue Hook; James Hook
3.	Announcement of Awards The following members received awards. <ul style="list-style-type: none">• Adelaide and Amelie Bush – overnight hike• Harry Colgrave – sports education and employment• Ava Chant - bronze silver and gold achievement awards at school• Max Preece- NDIS and go cart racing.• Damon Hoole – work with Northcott.• Karen – 40 years in work and 30 years married.• Blake Wellbrock – leadership position at school• John Roberts – transition to a new aged care facility• Dean McMahon – travel independence Volunteers The Association gratefully acknowledges the service of all of the volunteers at, for example, Disability expos, HealthEd, Fundraisers, GP education days etc. Also, for particular service: Janine Peate – Facebook group Phil Eastbury -Moderation of FX Dads Zoom support group Kate Stokes – Graphic design for FXAA awareness and educational materials
4.	Minutes from AGM 2021 The minutes of the AGM held 21 November 2021 were accepted without change. Moved Bruce Donald, seconded Graham Hook. All in favour.

5.	<p>The Annual Report of the Association for 2022 was posted on the website with notice of the AGM. It is available for download as a pdf.</p> <p>President's Report (Ted Brown)</p> <ol style="list-style-type: none"> 1. Strategic plan has been published. Thanks especially to Kate McKeand and Wendy Bruce 2. FMR1 gene has changed name to Fragile X Messenger Ribonuclear Protein (from Mental Retardation) 3. Despite COVID, the Association has expanded support via zoom, including peer support, webinar Q&A series. Also, more calls to the help line 4. Approval of prenatal genetic carrier screening – FX, CF, SMA commencing Nov 23 5. Following from the research work with Mackenzies mission 700 other genes are under consideration for adding to prenatal screening. 6. Special thanks to the Cunningham family for their generous support of FXAA over many years. Many thanks to VCGS, GOLD service, and Dr Jonathan Cohen for service and support over many years. 7. Thanks to all of the Board members for their ongoing voluntary service. <p>The meeting extended a vote of thanks to Ted for his service as President and grateful that he has agreed to continue working on the Board.</p>
6.	<p>Year in Review & Annual Report</p> <p>LIZ JEWELL expressed thanks to the Board and spoke about her work:</p> <ul style="list-style-type: none"> • offering Support, online or in person, offered to the Fragile X community Australia-wide • counselling sessions increased over time, and tailored to individual needs, addressing varied topics • Peer support groups are working well over Zoom <p>WENDY BRUCE gave a snapshot of other activities of the organisation:</p> <ul style="list-style-type: none"> • Webinar series a highlight, with 21 webinars to date, and plans to extend the content type and marketing of webinars, eg allied health. Some grant funding and donations have supported the webinars, with thanks to Zynerba Pharmaceuticals, Genea, Pine Property. 805 registrations to webinars • 10,000 views of website over past 12 months
7.	<p>Treasurer's Report</p> <p>A The Treasurer Adam Lawrence-Slater highlighted the following:</p> <ul style="list-style-type: none"> • The auditor's report is included in the Annual Report at pages 2-17 • At 30 June 2022, net assets of \$998,294 largely (76%) comprised the Endowment Fund net assets of \$760,746. Net assets decreased by 6% due to a decline in market value of the Endowment Fund investments. • He noted the importance of fundraising and donations which provides all of working the income for the Association. • 62% of expenditure is salary – 2 staff, and one part-time contractor (accounts) <p>Moved to accept the Annual Financial report: Karen Lipworth, seconded Mandy Barker</p>
8.	<p>Appointment of Auditor</p> <p>The retention of the existing auditor, <i>Manser Tierney & Johnston</i> was moved by Adam Lawrence-Slater, seconded Kate McKeand. All in favour.</p> <p>mt</p> <p>A short video of 3 buildings of the 80 in Australia which were illuminated for World Fragile X Day on 22 July 2022 was played.</p>

9.	Election of Board Members
	<p>Noted: The organisation may have a maximum of 8 Directors, who may serve no more than 4 consecutive terms. The President may serve no more than 2 consecutive terms in that role but an additional 2 terms on the Board.</p> <p>Nominees for Re-election and Election were introduced and voting conducted:</p> <p>Prof Ted Brown – re-elected Cynthia Roberts – re-elected Kate McKeand – re-elected.</p>
	<p>Nominees for Election – new Board Member Alison Evans – elected.</p>
10.	<p>Other Business: A Look to the Future</p> <ul style="list-style-type: none"> • Clinical trials – Prof Brown summarised – treatment of symptoms, anxiety, cognition, Zynherba trial in Australia and US. Other trials Tetra pharmaceutical Company, Annabex • Cynthia Roberts summarised advocacy for prenatal carrier screening, genetic counselling, PGD, Newborn screening. • Karen Lipworth outlined the work of the <i>International Fragile X Carrier Registry</i>. A link to registry is on the FXAA website and will be sent to registrants of this meeting.
11.	<p>Other Business</p> <ul style="list-style-type: none"> • Webinars – continuing with some new and some repeat topics. • Education – speech pathology Australia will be developing a Fragile X module for speech pathologists. • Genetic carrier screening – The Association is working with key groups in publicising particularly before the commencement. • Advocacy will continue. We may need assistance from members with online surveys to collect data for our advocacy. • Potential for new pharmaceutical treatments for Fragile X syndrome. Key to getting new treatments is for support organisations to have a view of the numbers of people and importance of the treatment to those patients. • Thanks were expressed to Liz Jewell and Wendy Bruce for their dedication and hard work. • Bruce Donald moved a vote of thanks to the auditors, Manser Tierney and Johnston. • Special thank you Jaxon for appearing on the front cover of the Annual Report. • Xmas cards are again available for sale. • Handcrafted play equipment has been donated for raffle. Association will need to register application in different states for raffle.

Meeting closed 4:27pm

ACTION ITEMS

ACTION	RESPONSIBLE PERSON	TIMING
Nil		
Items from previous meetings		
Nil		